

“The citizen is stepping into a new role” – policy interpretations of patient and public involvement in Finland

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Abstract

Involving patients and the public in healthcare decision-making IS on the policy agenda in several countries. The aim of our study has been to describe and analyse the development of patient and public involvement from a policy perspective. We argue that the language of health policies can influence both the aims and the development of involvement methods. In this study health policy documents, which have guided the development of patient and public involvement in Finland have been analysed using methods of Membership Categorisation Analysis. This has enabled us to explore how health policy documents categorise patients and the wider public in relation to involvement and orientate the involvement activities in which people are able to participate. Different set of abilities, expectations, responsibilities, and opportunities are attached to the categories of *patient*, *risk group*, *service user*, *customer*, and *expert*. Health policy documents often equate involvement with choice making by service users and customers; or as involvement in service development by experts. In both of these cases, involvement is depicted as an individual activity that requires personal responsibility and specialist knowledge. Although involvement opportunities have overall increased, they are primarily available to people that are ‘participation ready’ and able to adopt roles promoted in policies. Health policy documents produce one interpretation of involvement, nevertheless it is important that diverse groups of patients, the public and health professionals participate in the discussion and express their views, which may differ from those of policy makers.

Keywords: Health Policy, Patient Participation/Role, Qualitative Research, User Involvement

What is known about this topic

- Patient and public involvement is a common trend in health policy and policy makers claim to be putting people in the driver's seat
- Involvement is a complex, dynamic process which can take different forms

What this paper adds

- policy categorisations of patients and the public can both enhance and limit involvement opportunities
- political agenda for increasing choice can be a powerful driving force in shaping involvement
- categorising people as customers and experts makes involvement a specialist and demanding task

Introduction

Patient and public involvement has established its position on the policy agenda (Martin, 2008). In Finland, similarly to numerous other western countries, policy makers have been promising to put people utilising health services “in the driver’s seat” (Tynkkynen et al. 2016). This rhetoric has been particularly common in relation to health services, which are the focus of this study. Despite becoming widespread, prior studies have demonstrated the complexities and variations of involvement as it has been adopted into health and social care policy and practice around Europe (e.g. Leppo & Perälä 2009; Lichon et al., 2015; Vrangbaek, 2015; Pavolini & Spina, 2015)

Patient and public involvement in healthcare has historical roots ranging back decades with patient organisations and user groups promoting of patients’ rights to participate in decision-making (Beresford, 2010). Hence, at its core involvement entails demands for power sharing and self-determination. However, when translated into policy these concepts can be turned into something much less progressive or even counterproductive by policy makers (Stratigaki, 2004). Cowan et al. (2011) have argued that this has happened to concepts such as ‘social inclusion’ and ‘recovery’, which have been transformed to fit a quasi-market agenda. Indeed, the once passive and helpless patient has been reconstructed as active, self-reliant, and demanding critical consumers (Armstrong, 2014; Newman & Kuhlmann, 2007). Both increased access to health information and the growing influence of consumerism in healthcare have been contributing to this change and it is in this setting that involvement has risen onto the policy agenda. Hui and Stickley (2007) have highlighted the role of policy rhetoric in defining and guiding involvement.

In practical terms involvement can take a variety of forms including participation in *treatment decisions*; involvement in *service development*; *evaluation of services*; participation in *education and training* of health professionals and engagement in all aspects of the *research cycle* (Tritter, 2009). Additionally, there are opportunities for people to participate in the *co-production* of some services, which can offer a transformative way of developing services,

presuming it is not merely based on compliance or cost cutting (Needham & Carr, 2009). Arnstein's (1969) ladder of participation has been central in shaping the theoretical framework for involvement, describing a continuum of participation ranging from being informed to complete control. Nevertheless, it is also a hierarchical model, placing a great emphasis on power whilst failing to capture the complex, dynamic and evolutionary nature of involvement processes (Tritter & McCallum, 2006; Carpentier, 2016). Tritter (2009) has suggested an alternative way of conceptualizing patient and public involvement in order to differentiate between the aims, types, and methods of involvement activities. This conceptualization divides involvement into indirect and direct forms, where the former entails gathering information from service users and the latter entails that people have the opportunity to take part in actual decision-making. Involvement can occur on an individual level, such as deciding on a specific treatment, or a collective level, e.g. when a patient group takes part in the planning of a new service. Additionally, involvement can have both proactive and reactive dimensions, depending whether participants are able to participate in setting the agenda or respond to an existing one.

In this study, we will focus on the development of patient and public involvement in Finnish healthcare, from a health policy perspective. Over the past decade, there has been a policy shift towards implementing more involvement opportunities into healthcare. Nevertheless, we argue that these new opportunities are not evenly distributed and health policy language plays a part in orientating involvement activities. Indeed, the ways in which policies position patients and the public can orientate involvement by enhancing options for some whilst limiting them for others. Hence, through the analysis process, we are able to both challenge policy terminology and discuss the development and guiding principles of involvement among different groups. Prior to the policy analysis, we will briefly outline the development of involvement in Finnish health policies.

Development of patient and public involvement in Finland

Finland is a Nordic welfare state, based on ideas of universal rights to health and social care. However, patients' right to choose has risen high on the policy agenda, bringing to the fore the needs and agency of the service user (Leppo & Perälä, 2009). It has also been argued that business and economic interests have taken a guiding role in health policy (Ollila & Koivusalo, 2009). The Finnish healthcare system is complex with a highly decentralised administration, multiple funding sources, and three distribution channels in first contact care (Tynkkynen et al. 2016). On a primary care level, services can be accessed through municipal health centres, occupational health services, or private services. Local authorities are responsible for providing care through municipal health centres, with service users paying a co-payment for accessing services. Additionally primary care is organised through occupational health services, funded by the employers and employees, or people can choose to pay for services organised by the private sector.

Compared to countries such as the UK, the Netherlands or other Nordic countries, Finland is a relative newcomer to developing patient and public involvement in healthcare. During the 1990s, patient rights were strengthened by passing the Act on the Status and Rights of Patients (785/1992). This legislation enforced a direct, individual form of involvement by highlighting the rights to be involved in decisions about individual treatment and care. Additionally, people have been able to voice their opinions through indirect, collective ways such as voting in national and local elections. It has also been possible to engage collectively through patient organisations.

On a policy level, involvement received little attention until the latter part of the 2000s, when The *National Mental Health and Substance Abuse Plan* began to promote direct involvement and experiential expertise in service development. Following, involvement and particularly direct forms of involvement filtered into the general national level policies with the *National Development Programme for Social and Health Care Services* (2012) claiming that “*involvement and customer-orientation are the central principles*” (p.19). These programmes

were instrumental in linking involvement with health service development. Indirect, collective involvement opportunities such as participation in municipal residents' forum; and direct, individual opportunities such as "including service users in decision making bodies" and "planning and developing services together with service users" were also included in the Local Government Act (410/2015, 22§). Following the parliamentary elections in the spring of 2015, the newly appointed centre-right coalition government continued to include involvement into their Strategic Programme (2015) for health and welfare. They also embarked on a large-scale reform process of health and social care services coinciding and connected to a reform, which includes transferring responsibility for organising health services from municipal and local authorities to autonomous regions. These reforms are likely to impact on the forms involvement will take in the upcoming years.

Methods

In this study, the emphasis is on the policies and strategies, which have described and extended the idea of involvement in Finnish healthcare. In order to distinguish between different forms and varied aims of involvement the terms (direct-indirect, individual-collective) suggested by Tritter (2009) will be applied throughout. The questions we pose in this study are 1) what categories do policies construct for patients and the public in relation to involvement and 2) how do these different categorizations orientate involvement activities? The materials consist of key national health policy documents (n= 7) which have discussed and described involvement: the *National Mental Health and Substance Abuse Plan* (2009); *Finland's Disability Policy Programme* (2010); *Socially Sustainable Finland 2020 – Social and health policy strategy* (2011); the *National Development Programme for Social and Health Care Services* (2012); *Quality Recommendation to Ensure Good Aging and Improve Services* (2013); *Wellbeing is functional capacity and participation - The Future Review of the Ministry of Social Affairs and Health* (2014); and *Finland, a land of solutions – Strategic Programme of Prime Minister Juha Sipilä's Government* (2015). The first six documents have been the main national level

publications mapping out the policy aims and developments in health services, covering a range of different health sectors. The last document presents the current government's national policy goals in relation to health services. Additionally, all these documents describe and discuss the introduction and development of involvement in healthcare settings. All the documents are freely available online and have been published by the Ministry of Social Affairs and Health (MSAH), apart from the latter, which was published by the Prime Minister's Office.

We analysed the documents using methods of Membership Categorisation Analysis (MCA). In this study, categories are understood as being both cultural and context bound with particular qualities, expectations, responsibilities, rights and competencies attached to them (Juhila et al., 2012). Although categories may appear descriptive, in social interaction they also carry moral connotations (Jayyusi, 1991). Whilst conducting the analysis we have applied the principles suggested by Stokoe (2012). We began by *collecting* purposive data, i.e. national policies that discuss patient and public involvement in relation to healthcare. Following this, we *built* explicit mentions of categories (e.g. patient, customer, expert) and descriptions attached to them; *located* the position of categorial instances within the text; and *analysed* how the actions are orientated in relation to different categories. In other words, we focused on the involvement activities and opportunities were connected to different categorisations within the documents. Through this process, we were able to explore how certain categories were bound with certain activities, expectations, responsibilities and opportunities, as well as including moral connotations regarding individual responsibility over health and wellbeing. In the results section, the focus is specifically on the categories applied to people in relation to involvement in different aspects of healthcare.

Findings

"The citizen is stepping into a new role" announced the Future Review published by the Ministry of Social Affairs and Health (2014:15). This section explores these roles by focusing on policy documents that claim to enhance involvement opportunities and champion customer-

oriented care. Involvement has been developing within a policy context, which emphasises individual choice making and economic necessities to reform and reorganise health services. Involvement is championed as means to decrease social inequalities; enhance customer-orientation; increase efficiency and reduce costs. Over the past decade, there has also been a shift towards introducing a greater mix of involvement methods including indirect, direct, individual and collective forms of engagement. We have arranged the categorisations under three headings: 1) Categories which imply passivity and offer limited involvement options; 2) categories linked to activity, offering involvement through individual choice making and; 3) the expert category, which demands specialist knowledge but offers a wider variety of direct involvement opportunities.

The limited involvement options of patients and risk groups

There are no references to patients in parts of the documents where involvement is discussed, implying that active participation is neither expected nor encouraged from people categorised as patients. This creates a contrast between the category of patient, which the documents associate with increased need for care, and other categorisations associated with active agency.

Categorising someone as a patient does not inherently imply passivity; however, it is only applied in reference to people who require intensive long-term care in a hospital or care home setting. This implies dependence on services and potentially high costs, which are not viewed positively in policies that aim to reduce expenditure. It is also notable that, apart from these exceptions, the word patient in direct reference to people has almost disappeared from the documents and it is mainly used when referring to patient records or patient safety. The phasing out of the term patient can be seen as surprising as prior research has suggested that people still prefer to be referred to as patients rather than clients, customers or consumers (Deber et al., 2005). On the other hand, the disappearance of the term is likely to reflect the wider policy aim to reduce care dependency and construct people as active self-sufficient participants, which is perhaps easier to accomplish with alternative terminology.

Although the patient category has almost vanished, another potentially marginalising category titled risk groups is applied to people who are long term unemployed, prisoners, homeless, immigrants, ethnic minorities, poor, people with mental health or substance abuse problems and minority language groups. In relation to risk groups, involvement is promoted as a way to reduce social inequalities. However, the personal agency, capacity to make decisions or take part in development tasks are not supported by the policy language used to describe the risk groups.

“Targeted and encouraging methods which promote the health and wellbeing of risk groups are being developed and implemented together with the public sector, organisations and companies.” (MSAH, 2012:21)

Although the involvement of risk groups is promoted as an important policy aim, people belonging to risk groups are not described in terms that would emphasise collaboration or highlight them as valued sources of information and knowledge. On the contrary, the above extract positions public services, companies and organisations as the active agents attempting to promote the health of risk groups. This category exists within policy discourses of cost cutting, increased effectiveness and the requirement to take personal responsibility over one's wellbeing and lifestyle choices, making it challenging to interpret the categorisation as value free. It is also notable that although involvement is expected, the policies do not take into consideration the potentially varied requirements, which enable involvement among those who utilise health services. Overall, the policy stance towards involvement from people placed in these categories appears ambivalent, particularly in comparison to the other categories such as customers and experts.

Service users and customers – involvement through choice

Customer is the most common category applied throughout the documents. In contrast to patients and risk groups, customers are depicted as active, knowledgeable and driving forces of change. Despite this, involvement options for customers appear limited to individual choice

making and the customer category links involvement with the agenda of opening healthcare provision to private providers.

“The customer’s expertise is increasingly made use of in the development of social and health care services, in order for services to be customer-oriented. (...) Currently customers have the opportunity to choose their place of treatment only from the public sector. It is necessary to clarify how the right to choose has been implemented and assess whether this right should be extended.” (MSAH, 2014:15)

Nevertheless, there are subtle differences in this category relating to age groups. Discussion on children’s ability to participate is almost entirely absent from the documents. Whereas, elderly people, despite also being referred to as customers, are provided with more involvement opportunities than working age adults. Policies balance between describing older adults on one hand as active participants and on the other hand as people requiring protection and care. Those who are active and capable can get involved through collective means such as Elderly Councils and Citizens’ Jurys. Hence, the older adults capable of participating in these activities are more closely tied with the democratic process, but are mostly in a position to offer feedback, voice opinions and issue statements rather than set agendas. Additionally, branding healthcare users as self-sufficient customers raises several challenges, particularly in relation people who may lack capacity or require facilitation to participate.

Another category connected to involvement is that of a service user, which can be seen as less value laden than categories such as customer or consumer. Nevertheless, it has been criticised for providing a simplistic view of people merely as users of health services and fails to acknowledge the complex identities and multiple roles people inhabit (McLaughlin, 2009). The policy documents engage service users as developers and assessors. This presents new opportunities but also shared responsibility for service development.

“People’s roles are transforming into more active ones. The service user is also an evaluator and developer. People are placing new aims for customer relationships, service availability and mobility.” (MSAH, 2014:11)

Similarly, to customers, service users are described as demanding driving forces for change and willing participant in evaluation and development activities. Despite this, there is a lack of further elaboration on means through which evaluation or development could be undertaken. Although customers and service users are given increased opportunities, the categories are also bound with responsibility.

“Services are reformed as a whole in a way which involves users actively in their development. Service users need to be offered up to date and impartial information regarding treatment options and service providers. In this manner, users’ ability to bear responsibility over their health and wellbeing increases.” (MSAH, 2011:11)

This extract does not only introduce the commodified view these policies draw of healthcare services, there is an attempt to re-negotiate the division of responsibilities between the service users, service providers and the state. The emphasis is on personal responsibility that is connected to both customer and service user categories and can be viewed as examples ‘of neo-liberal methods of governing late modern societies through inculcating self-management and individualisation of responsibility’ (Crawshaw, 2012, p. 200). Health is depicted as a matter of choice and the individual is expected to shoulder the responsibility for their wellbeing. Service users appear subservient and are expected to accept both ‘impartial information’ and responsibility. There are also references to expertise, which is a new category in Finnish policies, but it can play a significant role in orientating the future development of involvement.

Experts by experience and peer support workers - involvement in service development

The idea of people possessing unique knowledge due to personal experiences is not new, however, it has not featured in health policies prominently until 2009 when the National Mental

Health and Substance Abuse Plan included the involvement of experts by experience and peer support workers in service planning and development as one of its main aims.

The involvement of experts by experience and peer support workers should be increased in the planning, implementation and evaluation of mental health and substance abuse services in order for the services to take customer/client requirements into more consideration. Peer support workers are people, who relying on their own experience, as volunteers provide for example long term support for customers/clients within the service system, operate in peer support groups, or as individual peer supporters. (...) Experts by experience are those people who have personal experiences of a mental health or a substance abuse problem either having suffered from it personally, having recovered from it or accessed services due to it or being a family member or a close relation. Experts by experience should be used in municipal strategy work, service evaluation and rehabilitative groups. They can be invited as experts into the governing bodies of service units. (...) Expert by experience activities and the associated reward systems should be developed jointly with organisations and municipalities.”
(MSAH, 2009:20)

The National Mental Health and Substance Abuse Plan differs in many ways from the other policies as it included clinical professionals and patient organisation representatives in its production. The follow up reports have even included experts by experience as co-writers. In contrast to the other documents, the plan placed a stronger emphasis on the democratizing potential of involvement and downplayed the economic arguments. Central to the categories of peer support worker and expert by experience is the usage of personal experience, but whereas peers support workers are expected to do this on a voluntary basis, experts by experience could be receiving pay for their work, which has potential to enhance the creation of hierarchies between involved patient groups. However, these categories also provide opportunities to engage directly with service providers, clinical professionals, and

political decision makers and make co-production of services a possibility. However, taking part in meetings and management groups is often undertaken on an individual basis, making this form of involvement individual rather than collective. Involvement at this level can also require a wide range of skills and knowledge, extending beyond personal illness experience.

In recent years, the idea of patient expertise and particularly the expert by experience role has been broadened beyond the field of mental health and substance abuse. In Finland, being able to adopt these roles generally requires training provided by patient organisations and hospital districts, ranging from a few days (for peer support workers) to several months (for experts by experience). Becoming an expert by experience or a peer support worker can offer a less stigmatizing category for those branded as risk groups in other national policies. However, questions can be raised about the capacity of those from disadvantaged groups to adopt these roles and about the potential professionalization of patients, as involvement is channeled through roles that require substantial training and long term commitment. These are some of the practical issues, which health bodies will need to consider if they wish to support effective involvement from a diverse group of participants.

Indications of future developments

The current government was appointed in the spring of 2015 and shortly afterwards they outlined their strategic priorities. Under the health and welfare section, involvement is linked with the aim of making services more customer centred (Prime Minister's Office, 2015). Concurrently, the Ministry of Social Affairs and Health has begun a project that aims to produce clearer definitions for involvement and enable experiential knowledge to filter more effectively to civil servants and policy makers (MSAH, 2017). Overall, the key strategy document continues the trend of referring to people as customers, which is in line with the government's vision to extend the right to choose service providers and increase the use of service vouchers in the coming years.

Notably, the expert by experience categorisation continues to be utilised, signaling that the position of experts by experience may be strengthened in the future. Currently experts by experience lack a clear position within healthcare and it has been left on to active health professionals and the voluntary sector to pilot new forms of involvement and create opportunities for experts by experience. At present experts by experience are e.g. working in some municipal health centres and community mental health services and participating in hospital and municipal executive meetings. Indeed, experts by experience currently have the most direct opportunities accessible to them. However, most of these opportunities are open to individual experts, with collective forms of involvement being less common.

Discussion

Despite policy documents claiming to champion patient and public involvement, the policy language describing involvement can be ambiguous. In this study, we have explored the use of categories, which national level health policies apply to people in relation to involvement. Through the analysis, we found that policies attach varied opportunities, abilities, and expectations to different categories. However, there appeared to be an underlying assumption that within categories healthcare users would have homogenous views and requirements. In most cases, involvement still occurs through indirect means, although during the past decade there has been an increase in direct opportunities. Indirect, collective forms of involvement include voting, or providing feedback by participating in citizen juries, councils, or panels. Direct, but mostly individual ways of engaging include becoming a member of managerial/planning/steering group. The opportunities for proactive involvement, where patients or the wider public are a part of agenda setting remain limited. Hence, for most people involvement is mainly about responding to pre-existing agendas.

During the latter part of the 20th century and early parts of the 21st century the role of the patient and their relationship to health professionals has undergone numerous changes, with patients being reconstructed as having active agency, skills and technical

competence (Armstrong, 2014). In our analysis, the passive patient had not completely vanished, manifesting itself partly in the risk group category, which existed in contrast to the customer and expert categories, where agency, skills, and competence were emphasised.

The ‘demanding and skeptical citizen consumer’ described by Clarke et al. (2007) is strongly present in Finnish health policies, following a similar trend to other countries (Newman & Kuhlmann, 2007; Sturgeon, 2014). Addressing people as customers and service users enables policy documents to position them as the active drivers of reform, modernization and increased choice. Choice coupled with increased competition is high on the current government’s agenda as it prepares for the upcoming health and social care reform. Indeed, the claim is that people are demanding for more choice, although the WHO survey on responsiveness in health care documented that only 6% of Finns considered choice as the most important aspect of non-clinical care (Valentine et al., 2008). Patients already have the opportunity to choose between municipal health centres and private healthcare providers commissioned by the municipalities, but less than 10% of the population have used this right (Sinervo, Tynkkynen & Vehko, 2016). Defining involvement merely in these terms can limit the future possibilities involvement could bring and creates a distinct possibility of choice becoming a proxy for involvement (Tritter, 2009). Applying consumerist categories to patients and the public has faced criticism, as there are few circumstances where individuals can accurately be classified as consumers in relation to healthcare (Goldstein & Bowers, 2015). However, the most recent category included in policy documents, the expert, could enable policy makers to argue that people do possess the knowledge, skills, and capacity to make informed choices, even within an increasingly market-orientated healthcare setting.

Nonetheless, the expert category can create new involvement opportunities for people otherwise described as risk groups. Those willing and able to adopt the expert role are able to take part in direct involvement activities such as strategy work, service evaluation or become members of governing bodies of service units. However, in order to bring out a wider selection of voices, it is important to acknowledge that increased professionalization of users

can lead to only choosing those who have the required competencies and capacity to influence (van de Bovenkamp et al., 2009). In order to engage marginalised groups there needs to be more proactive measures, but also capacity building in order for people to feel a sense of entitlement to participate (de Freitas & Martin, 2015). Failing to include marginalised groups can exacerbate health inequities as policies and services are increasingly adapted to the needs of vocal majorities (El Enany et al., 2013). This development would be in direct conflict with the clearly stated policy aim of reducing inequalities.

Despite policy documents naming involvement a central aim, Finland continues to lack a systematic approach to involvement. There are no guidelines or criteria for evaluation of involvement activities, although this could potentially hinder future development and create a lack of confidence amongst the public and health professionals. Policies do address some of the major issues such as the representativeness of those involved or how to engage ‘invisible’ groups or those who rely on others to facilitate participation. Overall, policies construct involvement on assumptions that patients are willing to participate; possess similar opinions; and are able to access relevant information. However, people experiencing pain and suffering due to their illness may not have this capacity (Moffatt et al., 2012) and even if they do, people may not want to participate. Development of involvement activities has thus far been largely reliant on active individuals, which means that there is potentially a great deal of regional variation in available opportunities and unclear guidance on how to facilitate involvement activities effectively on a practical level.

Although this study has focused on the health policy perspective, we acknowledge that different stakeholders possess varied views and aims, which are outside the scope of this study. If and when more experts by experience and peer support workers are integrated into decision making processes and service delivery, they are likely to have a stronger voice in how involvement should be developed further. The large-scale reforms taking place in Finland in the near future are also likely to impact on involvement. Local level legislation currently guarantees municipal residents rights to have a say on the development of public

services. Whether these rights will remain as the new regional authorities are formed is yet to be seen.

Conclusions

In this study, we have argued that although involvement has become a central theme in health policies, different policy categorisations can have consequences to the involvement opportunities associated with certain groups. In the Finnish policy context, involvement is intertwined with the political agenda to increase choice and competition. Policies have begun to categorise people as experts, suggesting that they possess experiential knowledge, which health services could utilise. Additionally, there are differences related to age categories, as the health policy documents do not apply involvement rhetoric to children. In contrast, involvement is expected of working aged adults and elderly people, but their opportunities to participate rely heavily on their ability to adapt into preferred categories and they are rarely in a position to set agendas. Issues such as evaluation methods, systematic planning and potential barriers, which can prevent effective participation and risk tokenism, remain unacknowledged. The upcoming large health and social care reform is likely to impact on involvement, making this a vital time for different stakeholders, including patient organisations, patient and the public as well as professionals working in healthcare services, to present their opinions and views.

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